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Review

Payment of Participants with Disability in Research: A Scoping Review and Framework

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Abstract: Payment of people participating in research is a common practice in research. Research ethics guidelines often require additional scrutiny of payment practices and research practices more generally for groups identified as vulnerable, including people with disability. However, the existing guidelines are vague, and often conflict, meaning that it is difficult for researchers to determine what is appropriate in relation to the payment of participants in research. This situation is addressed in this paper, which provides a review of the existing research on the topic of payment of participants considered 'vulnerable' in research. We followed a systematic approach to our scoping review, thematically analysed the data identified and reported our results according to the PRISMA-ScR guide for scoping reviews. Fifteen papers met the inclusion criteria and were included in this review. Where studies included empirical findings, most studies were based in the US and Canada, with a small number from European, African, and Asian countries. The key ethical concepts identified in the papers were consent, justice, and reciprocity, which were positioned in relation to coercion and concerns about undue influence from payment. The papers consistently identified economic precarity as being a shared factor across the groups identified as vulnerable which placed them at risk of coercion in relation to payment. The papers also strongly identified context as being an important consideration in both mitigating and enhancing risks around the payment of participants. A framework for considering the payment of participants is offered which responds to the areas identified in the papers. It focuses on the research environment, research situation, participant group, risks and benefits of the research, individual context, relational context, and research practices. This framework is provided as a resource for researchers considering the payment of people with disability in research, and those identified as vulnerable in research more broadly.

Keywords: disability; research subjects; payment; scoping review

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1. Introduction

People are often reimbursed for their participation in research through financial payments (e.g., cash or gift cards) and/or non-monetary items (e.g., course credits) (Brown et al. 2019; Grady 2005; Phillips 2011). Participants are paid in recognition of their knowledge and experience, and the time and effort that they contribute to research (VanderWalde and Kurzban 2011). Payment also increases research participation by incentivising participation (Blödt et al. 2016). Similar practices are in place across both qualitative and quantitative research. However, ethical concerns about payment practices, first raised decades ago, remain, and there is a lack of consistency around both the practices themselves and the principles through which decisions about payment should be made (Blödt et al. 2016; Head

2009; Macklin 1981; VanderWalde and Kurzban 2011). In particular, there are concerns around payment for participation in research with people in vulnerable groups (Fry et al. 2005; Polacsek et al. 2017; VanderWalde and Kurzban 2011), including people with disability who are often viewed as needing extra protections in research more generally (e.g., National Health and Medical Research Council 2007). This can lead to restrictions on payment for these groups over others (Polacsek et al. 2017), and can limit the ability for people with disability to participate in research where they are not receiving some form of payment or compensation (Warnock et al. 2022). This paper considers payment in relation to the vulnerability ascribed to people with disability in research ethics processes. The paper begins by examining the concept of vulnerability in research ethics and the ways that people with disability have been conceptualised as vulnerable. This sets the frame from which to consider the results of a scoping review of the research focusing on the payment for participants identified as 'vulnerable'. These results are then used to provide a framework for considering the payment of people with disability in research.

People with disability, including people with mental illness, are often positioned as vulnerable in national and international research ethics guidelines, which impacts on the way that they experience research participation (Aldridge 2019; Bracken-Roche et al. 2016; Snipstad 2022). They are usually included as part of a broader list of 'vulnerable groups' identified in the guidelines (Rogers 2013), which also includes Indigenous or First Nations groups, people living in situations where they have limited resources, people involved in criminal activities, and people living in developing countries (e.g., National Health and Medical Research Council 2007; Polacsek et al. 2017; UNESCO 2005). The usage of 'vulnerable participants' therefore provides a catch-all terminology which groups together people with very divergent characteristics with standardised approaches within ethical governance frameworks, such as the allocation of blanket allocation of heightened risk categories. Polacsek et al. (2017) lists the groups of people that necessitate special consideration in relation to payments in research as follows: "vulnerable participants include those who are socially or economically disadvantaged, people with a cognitive or mental disorder, hospital patients and their caregivers, people with a chronic or terminal illness, or are homeless". This list includes people with some forms of disability who are articulated to be at heightened risk in the context of payments related to research participation.

While vulnerability does exist in relation to disability (Garland-Thomson 2012), there has been growing criticism of the *assumed* vulnerability of people with disability and the presumptions underpinning the simple equation of disability with vulnerability. This critique, which draws on the social model of disability, comes from research in diverse fields, including disaster risk reduction (Connon and Hall 2021), technology (Beck 2024), care-giving (Capri and Swartz 2018), and law (Mustaniemi-Laakso et al. 2023). These critiques show that assumed vulnerability via blanket categorisations can lead to perverse outcomes which actually disempower people with disability, infantilize them, or create additional barriers for participation. Scully (2013) articulates the different dimensions of vulnerability in disability which can lead to the classification of people as in need of additional protections in decisions about research. She articulates these as inherent (e.g., health problems associated with particular disabilities) and contingent, which relates to vulnerability which is contingent on the inaccessibility of spaces and contexts beyond the person with disability themselves (e.g., education systems, research processes). To this she adds a third dimension, 'global assumed' vulnerability, where one vulnerability that the person might have is projected onto the entire context of their life (e.g., a person with a lack of dexterity which may make someone vulnerable in one setting means that they are ascribed as vulnerable more generally) (Scully 2013). It is this latter perspective on vulnerability that is most appropriate when considering the way that people ascribed as 'vulnerable',

including people with disability, are considered in ethical processes and frameworks. This is because the decision to classify disability as 'vulnerable' is based on a characteristic which may not be present in the individual at the time of the research. For example, an individual with psychosocial disability may not have an enhanced vulnerability in the context of paid research where they are providing feedback on meal options in a mental health support service, but they would have additional vulnerabilities when involved in paid research testing new medications, because of the possible drug interactions involved in such testing. This latter vulnerability is, however, shared with multiple groups of possible participants because receiving medications is not a characteristic solely associated with people with mental illness. Research ethics proscriptions which link global risk to particular groups may therefore place additional restrictions on research participation and payment on these groups and potentially miss the needs of other groups. In the case of people with mental illness, they can also reinforce the existing stereotypes about lack of capacity or competency in decision-making (Bracken-Roche et al. 2016; Ottati et al. 2005). This approach aligns with contextual approaches to the conceptualisation of vulnerability in relation to people with disability that have questioned an 'ontological vulnerability' where vulnerability is positioned as an integral aspect of disability (Arsenault-Gallant 2025; Scully 2013).

The ascription of people with disability as vulnerable means that they are then subject to additional 'protections' or ethical processes (Scully 2013). For example, in the case of Australia, all research involving people with mental illness as a key population is classed as having more than 'low risk' (even where the risk is negligible, as in the example above) and goes to a full ethics review process (National Health and Medical Research Council 2007). Additional scrutinies are applied to issues related to consent, particularly in relation to coercion, informed consent, and capacity. A consideration of these factors is not problematic per se, but may create the conditions where people who are considered inherently vulnerable under such guidance, including people with disability, are routinely excluded from research (Rogers 2013). It can also mean that, when they are included in research, their full and free participation may be more limited than it is for other groups. For example, where people with mental illness are characterised as vulnerable, this is often linked to a presumption of a lack of competency which, when enacted through institutional research ethics committees, can mean that their choice to participate in research is limited, or delegated to others, such as medical practitioners, who are able to judge competency based on their own criteria (Cseko and Tremaine 2013; Stineman and Musick 2001). This follows through to payment decisions, with Polacsek et al. (2017), for example, advising in their guidelines for nurses that researchers should "consider whether it is appropriate to conduct a pre-consent assessment of vulnerable participants, to ensure they understand the implications of participating and can give informed consent". There are serious consequences for not including people with disability—and people who are classed as vulnerable more broadly—in research; for example, by not including individuals routinely in clinical trials, we do not know whether the interventions being trialled are safe for them (Feldman et al. 2014).

Restrictions placed by research ethics committees on the inclusion of people with disability in research leads to systematic exclusion of this group from research (Bracken-Roche et al. 2016). There can be a multiplier effect where people with disability are already more likely to be absent from research because of other factors, such as poverty, location (e.g., within low- and middle-income countries), and the need for disability accommodations (Jagoe et al. 2021). This is problematic because it means that there is less research available that represents a broad view of the experiences and needs of people with disability. This means, for example, that health systems research, which aims to interview people about new ways of engagement to improve patient outcomes, may not lead to these results for

people with disability if it does not include them. This conflicts with the principle of justice as it does not allow all groups to benefit in an equal way from research (Mertens 2012). Following Fricker (2007), it can also lead to hermeneutic injustice because the experiences of people with disability may then be excluded from being *known about* through research. Proxy exclusion, where groups of people are not excluded, but barriers to inclusion are so high that they are not routinely included, has been rendered more possible by guidelines which argue that, because of the additional risks to people who are in a vulnerable group, they should not be included in research except where it is not possible to exclude them (e.g., National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979; World Medical Association 2013). This conflicts with the United Nations Convention on the Rights of Persons with Disabilities which emphasises the fundamental principles of dignity, equal participation, and accessibility. Article 31 calls for data on disability to be collected and specifically to include people with disability in this. This paper considers the payment of people with disability in research (both research focused on disability, and research more generally), against these ongoing unresolved concerns about the positioning of some groups of people as 'vulnerable' in research. It aims to critically examine the practices and reasoning related to the payment of 'vulnerable' research participants within the existing published research in an attempt to map out a framework for determining payment practices in relation to people with disability. This is offered both to support researchers, and to prompt further discussion about how payment is constructed in relation to people with disability and people designated as vulnerable in research more broadly.

2. Materials and Methods

A scoping review was identified as the most relevant methodology for this study given that it had a broad exploratory focus which made a systematic review impractical (Williamson et al. 2020). This review followed the widely used five-step methodology for scoping reviews identified by Arksey and O'Malley (2005), which includes the following steps: (1) identifying the research question, (2) identifying the relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarising, and reporting the results. The scoping review methodology and reporting in this article follows the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews (PRISMA-ScR) guidelines (Tricco et al. 2018). Closely following this methodology and reporting framework by the academic researchers, who have extensive previous experience in scoping review methodology, supported the rigour of the study. In this article we use the phrase 'people with disability' because that is the preferred term used by people with disability in Australia (People with Disability Australia 2025). We acknowledge that this is not a universally preferred term, and that there is contestation around its appropriateness in other contexts.

Aligned with the topic described above, the research question asked is as follows: what can the extant published peer-reviewed literature tell us about the ethical perspectives and research practices relevant to the payment of participants identified as 'vulnerable' in research? The research question was refined iteratively in relation to initial testing of the search strategy, where the results were examined for quantity and utility, and then the question expanded to one where there was likely to be a reasonable amount of data available to answer the question. This resulted in the question being expanded to consider 'vulnerable' groups more broadly, rather than disability solely, as there was a lack of existing literature on the latter participant group. Based on this research question the following inclusion criteria were developed: the paper was a peer-reviewed journal article or conference proceeding paper, was published in English, years = 2002 to 2023, and focused

on the topic of vulnerability in relation to the payment of participants in research (i.e., was a main aim of the paper, or otherwise discussed in a way where conclusions were drawn on this topic).

Via consultation with an academic liaison librarian, the following databases were identified as those most likely to provide a broad view of the topic and result in an identification of the extant literature: Web of Science (all databases), Scopus, Informit (all databases), and Sociological Abstracts. The base search strategy was: vulnerab* OR disab* AND payment AND research AND participant*, with the following database-specific refinements: Web of Science (TS = title, abstract, keywords); Scopus: (=title, abstract, keywords); Informit: (=all fields); Sociological abstracts: (NOFT = anywhere except full text—includes abstract, etc.). The search was conducted in 2023, and the identified studies (n = 414) were uploaded into the Covidence systematic review management software where duplicates were removed (n = 189) and an initial abstract-based relevancy review of the remaining 225 records was undertaken based on the inclusion criteria. Two hundred records were removed at this stage in the review, leaving 25 records for full-text screening. The full text of the publication was identified for 24 studies, and 10 studies were subsequently removed because they did not meet the inclusion criteria. We did not assess for quality in line with the PRISMA-ScR guidelines. Figure 1 below provides the PRISMA diagram for the study selection stages.

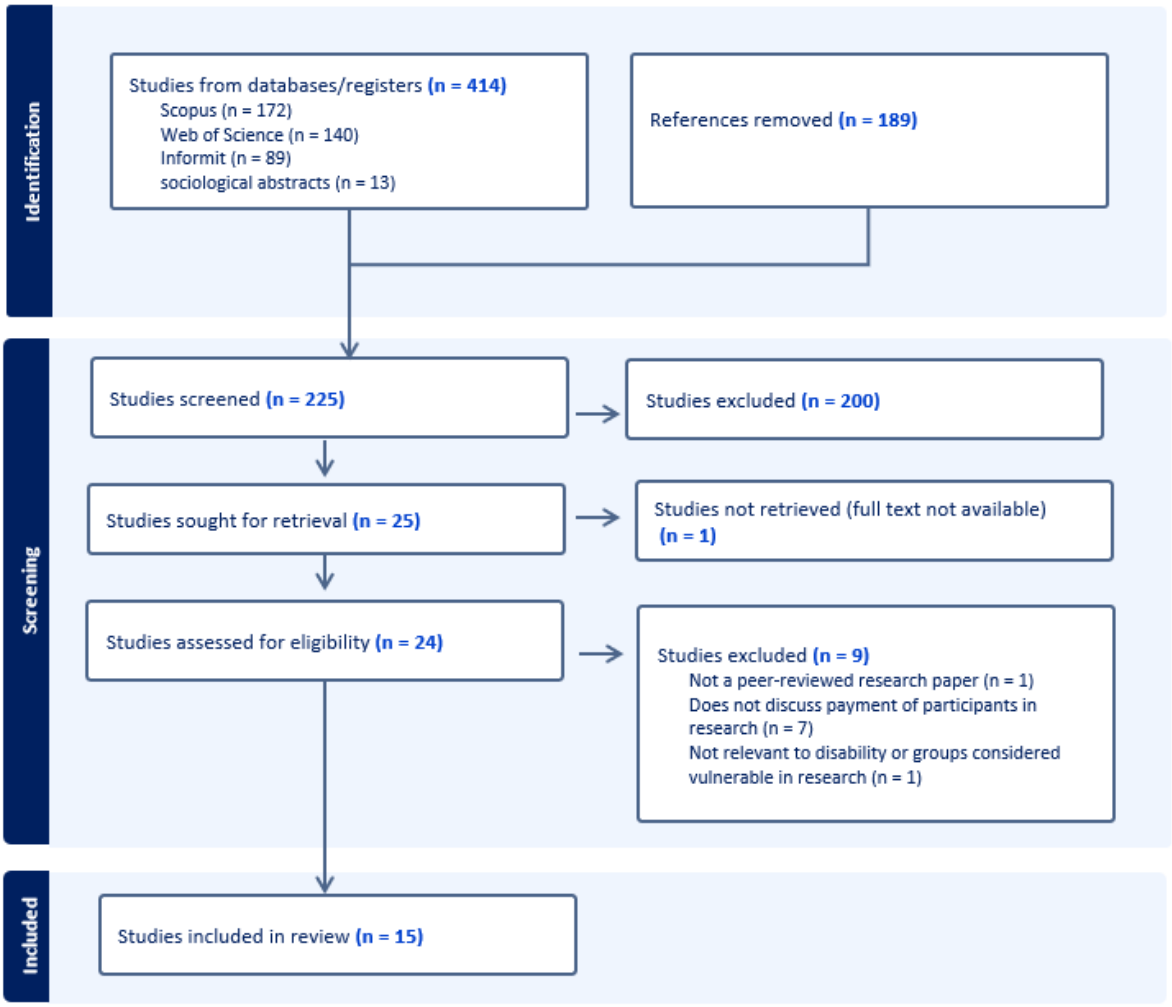

Figure 1. PRISMA chart.

An extraction framework was developed which was used to extract the relevant data from each paper. This included the following fields: authors, title, abstract, study location, study population, study context (i.e., general topic), methods utilised in the paper, limitations of the paper, practical ethical practices, risks of payment, benefits of payment, ethical or practical guidelines, ethical frameworks or concepts, other details (areas not covered above but important for answering the research question). Once these data were extracted, they were downloaded to an excel and word document, where the results were thematically analysed in relation to the research question. A thematic analysis was undertaken by the lead author and conducted inductively but focused on themes relevant to the research question, which aimed to understand the dimensions of decision-making relating to the payment of participants identified as 'vulnerable' in research. The resulting analysis was then written up in a narrative which brought out the main themes identified across the papers. This narrative forms the basis of the results and discussion sections below.

3. Researcher Positioning

The paper is written from the perspective of both personal lived experience of disability and allyship, with the lead author having worked for many years in partnership with researchers and communities with disability. They have also been involved in developing national ethics guidelines and as a member of an institutional HREC for almost a decade. They are the primary carer of a family member with disability. The second author has lived experience of disability and has over a decade of experience in research which considers the inclusion of people with disability, including within academic research.

4. Results

Most papers were focused primarily on the payment of participants in research with one discussing this as a key topic in a more general paper on research ethics. Only two papers were focused specifically on people with disability or their families as vulnerable groups in relation to payment (Dunn et al. 2009; Song et al. 2023). Other 'vulnerable groups' focused on included children (Blake et al. 2011; Song et al. 2023), people who use drugs (Bell and Salmon 2011; Collins et al. 2017), people in developing countries (Ballantyne 2008; Milford et al. 2022; Swan and Long 2011), older people living in poverty (Cook and Nunkoosing 2008), and economically vulnerable people (Gelinas et al. 2020). Several papers were focused on normal healthy volunteers (Iltis 2009; Tishler and Bartholomae 2002; Walker et al. 2023). The latter group was a surprising inclusion given the review focus on vulnerability; however, this research focused primarily on hidden economic vulnerability in relation to 'healthy volunteers', which was seen to unduly induce research participation in the context of payment, as discussed further below. Two papers concentrated on the payment motivations of researchers generally (Roca and Bates 2014; Surmiak 2020). Table 1 provides an overview of the main features of the research papers included in the review. Most papers were from countries where English is an official language, which is not surprising given the English language inclusion criteria. Six papers were from the US or Canada and only three papers included a discussion of low- and middle-income countries.

In terms of a structuring environment for payment decisions in relation to vulnerable groups, papers referenced several guidelines or reports as being important or instructive. The majority of the guidance referenced was from the United States (US). Four papers (Gelinas et al. 2020; Iltis 2009; Tishler and Bartholomae 2002; Walker et al. 2023) discussed the 1978 Belmont Report produced by the US government's National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research as being a significant guiding document due to its specific articulation of concerns around payment:

'coercion' and 'undue influence'. Two of these papers also referred to US Food and Drug Administration guidance (Tishler and Bartholomae 2002; Walker et al. 2023), which also focuses on those two concerns. The U.S. Office of Human Subject Research Protections was also cited as providing guidance that considers how the payment of participants may undermine consent (Gelinas et al. 2020; Tishler and Bartholomae 2002). In South Africa, the payment of participants in research is covered by the National Health Research Ethics Council (NHREC) guidance which states that much of the population should be considered vulnerable as a result of socio-economic vulnerabilities. They have developed a framework for considering payment for participation called the TIE formula: time, inconvenience, expenses (Milford et al. 2022), which should be used in decision-making around payment. The Nuffield Council on Bioethics was cited as important in the UK context. It provides the following guidance: "The payment of reasonable expenses incurred by the participant, or remuneration for loss of earnings suffered is generally considered to be acceptable and may be necessary in developing countries where high unemployment means that participants are only able to take part in research programmes with such support" (Ballantyne 2008). Blake et al. (2011) looked specifically at the guidance covering clinical trials. The European Union is covered by the Clinical Trials Directive 2001/20/EC, and the US is covered by the US Clinical Trials Directive 2001/20/EC. The International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) focuses on clinical research regulations and harmonises regulations in the US, the EU and Japan. All of these documents say different things about the payment of participants, with the ICH approving reimbursement generally, US guidelines commenting that payment is fine as long as it does not induce involvement and the EU guidelines banning "inducements or incentives, but allow[ing] compensation" related to "time and expenses" (Blake et al. 2011). The variation in advice within the guidelines demonstrates a lack of consistency around what comprises ethical practice in the payment of participants that goes beyond the payment of groups considered vulnerable in research.

Table 1. Included article summary.

Author(s) and Date	Study Location	Low- or Middle-Income Setting	Study Population	Context of Study	Methods
Blake et al. (2011)	US, Japan, and European Union	No	Children as participants in clinical trials.	Examines the creation of harmonised guidelines for paediatric clinical trial research. Focus on research broadly but discusses payment as part of this.	Commentary based on comparative policy analysis. Discussion of regulation with examples.
Song et al. (2023)	US	No	Parents of children with developmental disability vs. those without.	It is about retention of parents of children with developmental disability in studies generally. Discusses payment as part of the overall paper.	Quantitative methods. Secondary data analysis examining retention data from a longitudinal study.

Table 1. *Cont.*

Author(s) and Date	Study Location	Low- or Middle-Income Setting	Study Population	Context of Study	Methods
Collins et al. (2017)	Canada	No	People with HIV who also use drugs.	Focus is on equity in compensation and the place of compensation in research for this group, who are often positioned as vulnerable.	Qualitative. Focus groups.
Milford et al. (2022)	South Africa	Yes	People involved in clinical trials.	Examines how participants spent money provided to them for participation in research. Examines acceptable reimbursement levels.	Mixed methods—qualitative and quantitative. Questionnaire and focus groups with women involved in a clinical trial.
Bell and Salmon (2011)	Canada	No	Women who use drugs.	Talks to women who use drugs about their motivations for being involved in research and attitudes to research participation, and ideas about what ethical research is in their context.	Qualitative. Focus groups.
Dunn et al. (2009)	US, San Diego	No	Middle aged and older people with schizophrenia in supported accommodation.	Uses scenarios to understand how incentives operate in relation to choices about research participation for people with schizophrenia.	Quantitative. Vignette-based survey responses.
Cook and Nunkoosing (2008)	Australia, Melbourne	No	Older people living in poverty.	Reflects on research where participants were provided payment and the impact of this on the research encounter. Interested in how this impacts the interview.	Qualitative. Interviews and reflexive response.
Swan and Long (2011)	India	Yes	Non-government organisations, funders, recipients of development in rural communities in India.	Looks broadly at ethical issues in ethnography in developing countries but includes a discussion of payment.	Critical reflection on an ethnographic study.
Ballantyne (2008)	Developing countries	Yes	People in developing countries.	Examines exploitation and inducement in international externally sponsored studies conducted in developing countries.	Expert discussion. Critical discussion based on examples.

Table 1. *Cont.*

Author(s) and Date	Study Location	Low- or Middle-Income Setting	Study Population	Context of Study	Methods
Walker et al. (2023)	No specific location	No	Healthy volunteers.	General discussion of ethical criteria in phase one 'healthy volunteer' trials but discusses payment as part of that.	Expert discussion.
Tishler and Bartholomae (2002)	No specific location	No	Normal health volunteers.	Examines payment and motivations of 'normal healthy volunteers' and possible economic vulnerability.	Qualitative. Narrative literature review.
Roca and Bates (2014)	United Kingdom, East Midlands	No	Health research stakeholders.	Considers health researcher views on payment, including reasoning for payment and rates of payment.	Quantitative. Survey of health stakeholders.
Surmiak (2020)	Poland	No	Researchers.	Researchers who conduct qualitative research with people in vulnerable groups to understand their motivations for and against payment.	Qualitative. In-depth interviews.
Iltis (2009)	US	No	Normal health volunteers.	Addresses low payment in the context of recruitment.	Expert discussion.
Gelinas et al. (2020)	No specific location	No	Economically vulnerable individuals.	Discusses economic vulnerability in relation to payment, particularly in research undertaken in areas to reduce costs.	Expert discussion.

The key ethical concepts underpinning the discussion about the rightness of payment or certain types of payment included consent, justice (including fairness), and reciprocity. Coercion, linked to influence and 'undue' inducement, was the key ethical concept referenced in the papers. This was linked to consent, with the concern being that payment would provide inducement for participants to consent to research that they were not interested in or would put them at risk (Ballantyne 2008; Bell and Salmon 2011; Dunn et al. 2009; Gelinas et al. 2020; Iltis 2009; Tishler and Bartholomae 2002; Walker et al. 2023). For Blake et al. (2011) this extended to parents making decisions about whether children should participate in research, with concerns being raised about possible inducement due to the economic vulnerability of some groups of parents. Song et al. (2023) found that parents of children with developmental disability were more likely to be retained in studies if they received higher payments relative to wage, particularly if they were from diverse racial and ethnic groups. The same effect was not seen in parents of children without developmental disability (Song et al. 2023). Ballantyne (2008) discussed coercion in depth in relation to clinical research with people in developing countries, articulating a "tension between exploitation and undue inducement". Without payment exploitation was a risk where research is conducted in low-cost developing countries, and the results of the research are not shared with local populations. However, where there was payment, the relative

poverty of the population meant that there was a greater risk of inducement (Ballantyne 2008; Milford et al. 2022).

Dunn et al. (2009) conducted a qualitative vignette-based study which tested whether people with psychosocial disability (in this case schizophrenia) may be more at risk of coercion because of concerns about capacity to consent more generally. They found that, while to some extent they would participate in more risky research for greater payment, people were still able to decide not to participate where there were significant risks even where the payment level was high. They considered that it may be the economic vulnerability, rather than necessarily the participant's disability, which impacted their ability to freely consent in the face of payments. This concern is linked to justice, because payments may mean that people who are more disadvantaged are more likely to participate in research, which does not evenly spread any potential risks of the research across the community (Dunn et al. 2009). Justice was also a concern of Iltis' (2009) study which considered economic vulnerability in relation to the choice of 'normal healthy volunteers' to participate in phase one clinical trials, which is the first phase of trials to involve people. As with Dunn et al. (2009), they argued that low payments may mean only people who are in lower socioeconomic groups may choose to participate, which violates justice. Gelinas et al. (2020) found that the payment of participants could not effectively address a history of systemic *in*justice by providing payments that were too high. Payment was not viewed as a credible response to past practices, which could only be addressed through more broadly sharing the benefits of research. Justice was also framed as 'fairness' or 'fair compensation for service' (Walker et al. 2023); however, what was considered fair could only be assured by considering the context of research, not broad principles, because fairness is a relational concept (Gelinas et al. 2020). A contextual notion of the ethics of payment was emphasised as it was able to consider the lived intersectional realities of the participants (Collins et al. 2017), and the need to be sensitive to the cultural contexts around payments (Swan and Long 2011). This contextual understanding was viewed as particularly important where the research was taking place in developing countries (Ballantyne 2008; Gelinas et al. 2020; Swan and Long 2011).

Reciprocity is an ethical principle linked to compensation, characterised as benefit in return for time, effort, personal expenses, and service (Ballantyne 2008; Blake et al. 2011; Collins et al. 2017; Dunn et al. 2009; Gelinas et al. 2020; Milford et al. 2022; Walker et al. 2023). 'Compensation' is often used interchangeably with 'financial payment' in these papers (e.g., Collins et al. 2017), but financial payment is mentioned as just one form of possible compensation. Other forms of compensation include non-financial forms, such as access to medical care not otherwise available (Cook and Nunkoosing 2008; Milford et al. 2022; Tishler and Bartholomae 2002). One paper commented that people with a particular condition or disability do not need payment because they are being involved in the research for their own benefit: "It is understandable when an individual inflicted with some type of illness (e.g., a patient) seeks relief or cure for his or her condition by volunteering to participate in a clinical research trial" (Tishler and Bartholomae 2002). There were concerns, however, that medical-related non-financial compensation in clinical studies may be potentially more coercive for 'vulnerable groups' because disadvantaged participants may be so desperate for medical care for their untreated condition that they take on risks (Ballantyne 2008; Gelinas et al. 2020). Gelinas et al. (2020) argued that concerns about coercion can be addressed by strengthening the processes of consent through building improved communication between researchers and potential participants. This would also help to address the different frames through which payment might be viewed by researchers and participants, where researchers may have different assumptions about why

people participate, and the role payment plays in relation to reasoning around participation (Bell and Salmon 2011).

Effective decision-making surrounding payment is viewed as balancing effort, time, experience, and risk against financial payment and/or non-financial reward. It becomes unethical when this balance is not met, which results in exploitation (Ballantyne 2008; Collins et al. 2017; Gelinas et al. 2020; Walker et al. 2023) or the commodification of research (Surmiak 2020), such as, for example, when parents involve their children in research purely for financial reasons (Blake et al. 2011). Some papers considered that the commodification of research was potentially ethical, particularly where people had no other means of gaining financial payments and when their knowledge was highly valued by researchers (Bell and Salmon 2011; Collins et al. 2017; Cook and Nunkoosing 2008). Payment is justified as an appropriate form of compensation because it places traditional economic value on the experience of participants, particularly for those who have not been economically included in society. It shows that they have a unique and valuable contribution that should be worth compensating for (Collins et al. 2017). However, the literature warns that such commodification can possibly distort the way that information is provided by participants in research (Cook and Nunkoosing 2008; Surmiak 2020). Commodification was viewed as important in incentivising research that participants may otherwise never be involved in, such as trials involving 'normal healthy volunteers' (Tishler and Bartholomae 2002).

Various amounts of payment were proposed either within papers, or within the government guidelines cited. Collins et al. (2017) asked people with HIV who also used drugs what a reasonable payment would be. They found that cash was more useful than gift cards which can be hard to use for some groups, with USD 20–30 a fair amount, or USD 10–15 an hour. Some researchers were concerned that the provision of cash over gift cards would lead to people in vulnerable groups, like homeless people or 'addicts', spending their money in problematic ways (Surmiak 2020). However, others viewed it as paternalistic to restrict the mode of payment, for example, by providing gift cards that could only be used in certain ways (Bell and Salmon 2011), and that restricting payment to such gift cards could mean that people were not properly compensated, which could increase their vulnerability (Collins et al. 2017). In the South African study, clinical trial participants said that between ZAR 150 (USD 10) and ZAR 350 (~USD 24) was an appropriate amount (against a background monthly wage for the participants of between ZAR 0 and ZAR 12,000 (~USD 0–827), average wage of ZAR 1000 (~USD 69)) (Milford et al. 2022). This was a figure similar to the South African NHREC guidelines. In a study conducted in rural India, partnering NGOs either did not allow payment because of the cultural inappropriateness of offering payment for voluntary work, or set the payment at INR 200 (~USD 2.50) to individuals involved in ethnographic fieldwork (Swan and Long 2011). Aligning with the contextual approach discussed above, there was an understanding that payment levels should recognise and be dependent on local norms (Gelinas et al. 2020; Milford et al. 2022).

5. Discussion

This exploration of the existing literature shows that the concept of 'vulnerability' is applied to groups, including people with disability, in a way that impacts the practices of research. When vulnerability is considered in the context of the payment of participants, concerns are mostly centred around fears that the payment may be coercive and cause undue influence in the consent process for participation. The review identified key ethical perspectives and a small number of practical strategies which can be considered by researchers when thinking through ethical practice. The key elements of these findings are described here in relation to the broader literature, from which a potential framework for decision-making is posited.

5.1. Factors Influencing Decision-Making Around Payment

While the groups identified as potentially vulnerable differed across the papers, the papers consistently identified economic precarity as a shared characteristic of vulnerability. Economic precarity was viewed to be heightened for some groups because of the socio-economic conditions that they are routinely subject to, and because of the personal or broader social contexts in which they live. People with disability regularly experience economic precarity. This is due to the combined experiences of marginalisation as a result of social stigma, their regular exclusion from open employment, and a lack of access to mainstream health and social support services, including education. In Australia, for example, people with disability are routinely excluded from employment with a large gap existing between the employment rates for people with and without disability (Mellifont et al. 2023). This means that many people with disability rely on welfare payments for income and, even when they are employed, they are often employed in disability enterprises that are legally allowed to pay below the minimum wage (Steele 2023a, 2023b). This leads to levels of poverty which are much higher than for people without disability (Soldatic 2018). In Australia, for example, 45% of people with disability live in poverty (Steele 2023b), compared to 14% without (Davidson et al. 2022). This is an external vulnerability that people with disability have because of the social context in which they live, not an intrinsic vulnerability related to their disability. It is a contextual vulnerability that applies in most contexts because of the near-universal marginalisation of people with disability. However, because it is a contextual vulnerability it can be mediated in the research context through ethical practice, with payment practices constructed in such a way that the payment to participants can consistently take place.

Context was a consistently shared factor identified across all papers, being key to determining the ethics of the payment of participants. The context of the research, the individuals involved, and the research environment were all mentioned as factors important to consider part of decision-making around the payment of participants in research. These factors combine to create the environment in which the payment decision is made. A contextual approach has been considered in broader thinking on the positioning of vulnerability in research ethics decision-making (Rogers 2013) and is important for countering the norms of payment that come, for example, from European or US settings, being imposed in very different cultural contexts. The importance of this approach has been highlighted in the guidelines from international rights-based organisations. For example, while UNESCO's Universal Declaration on Bioethics and Human Rights still identifies people with disability as a group that may have special vulnerabilities, the UNESCO International Bioethics Committee has highlighted the importance of a contextual approach to such vulnerability, where people may have heightened vulnerability in some types of research and not others (UNESCO 2005, 2013). This rights-based 'contextual approach' linking heightened vulnerability to the research context is important. For people with disability, the context in which the research takes place can either reinforce the harm, exclusion, and disabling attitudes inherent in the long history of research *on* people with disability or value people with disability for their knowledge (Bailie et al. 2023). Valuing people for their knowledge means the co-creation of a research environment surrounding data collection in which people with disability are integrally involved (Kuper et al. 2021; Smith-Merry 2019). This environment extends beyond the singular research project, to the broader academic or community context in which the research is situated (Lindsay et al. 2023; Mellifont et al. 2019). If people with disability are valued in those environments, including where possible by leading the research that concerns them, then those environments are more likely to produce research protocols where the conditions of payment are ethical in relation to the context of the people with disability involved. They are also more likely to consider

accessibility, including in supporting decision-making and communication which can assist with consent processes (Bailie et al. 2023).

Other contextual factors which are important include the rate of payment in relation to local economic conditions or norms (Gelinas et al. 2020; Goyal et al. 2017), and the means of compensation being relevant to the participant population (Collins et al. 2017). Assumptions must be clearly assessed to ensure that generalisations are not made based on the location of the participant group as the acceptability of payment may vary even within the same project location. In their discussion of payment for community members involved in co-produced research in North India, Pillai et al. (2023) found that community members had mixed reactions to being paid but found overall that payment facilitated involvement in co-produced research. At a research project level, contextual factors relate to both the cultural and economic conditions of the population, and the physical and psychological 'riskiness' of the project, either in general or with respect to people with disability. For example, research that asks individuals to talk about institutional abuse against people with disability is going to be more personally risky to people with disability than to a member of the community in general, and it will also be more risky in contexts where individuals are not free to speak out against state institutions because of the political environment. Whether or not this is the case, however, is only understood by engaging with the community and, where possible, building the research in partnership with them (Smith-Merry 2019). The most serious concern raised in the papers about the payment practices in research within low- and middle-income countries was that the researchers moved the research into these settings because they would be cheaper and the individuals would be more willing to take up risks as a trade-off for payment (Ballantyne 2008; Milford et al. 2022). An important analysis within Ballantyne's (2008) paper was the way that it drew attention back from the individual to the community in which the research took place. As with Pillai et al. (2023), the application of a community-based perspective for considering harm and benefit helps to reframe the discussion in a way that better understands the needs of the community and the socio-economic environment surrounding the decision-making process for the payment of participants (Ballantyne 2008). Where cultures and communities have been collectively harmed by the colonial and moral perspectives embedded in practices of past research, including minority communities in high-income countries, it is also important to consider risk at a community level, and to ensure reciprocity also considers these past wrongs. Importantly, reciprocity for communities is not always just about financial resources, but about partnering for research outcomes (Vanyoro 2023). However, this perspective was not universal, and Milford et al. (2022) highlighted the different financial circumstances of women even in the same population groups, which meant the payments had different value and utility to the women depending on their own situation. This too is an important reminder for researchers to engage deeply with communities to understand the different motivations of participants, and whether payments will entice them to accept unacceptable risks, rather than applying a generic risk to participants in low- and middle-income countries.

5.2. Key Ethical Concepts

Within the papers included in this review, the key ethical concepts brought into the discussion of vulnerability related to consent, justice, and reciprocity. These each add a lens through which to consider the ethics of the payment of participants in research, but they also add a tool that researchers can use to determine the practical ethics of their payment framework. For instance, justice should be considered a key principle for understanding whether payment leads to the unfair targeting of one group in research over others (Walker et al. 2023) or whether it leads to epistemic injustice by excluding

some forms of experience from academic knowledge-making. However, what is fair or 'just' is also fundamentally contextual in nature, with what is fair being dependent on the research context, the participant context, and the socio-cultural context surrounding the research (Gelinas et al. 2020; Hunt and Godard 2013). Concerns about consent link to the concept of autonomy and general concerns about whether people with disability can freely consent in the same way as other 'non-vulnerable' participants. The concept of relational autonomy is relevant here (Ells 2001; Scully 2013). Relational autonomy addresses practices where decisions about consent for research are removed from people with disability because of global concerns about competency and dependency which are attached to the label of disability. As Scully (2013) observed in their articulation of 'global assumed' vulnerability, Ells (2001) points to the fallacy of such an understanding of 'dependency', arguing that "we are only dependent or independent with regard to certain specified tasks". Relational autonomy calls for practices which support autonomy and recognise and negotiate the individual's self-authority or independent decision-making, even where people may have significant impairment (Ells 2001). This discussion is relevant to the payment of participants with disability in research, because it compels the researcher to enter into a relational dialogue with the individual to communicate about what is involved in the research and what supports the person may need before consent is given (Gelinas et al. 2020). Such a process negates the debate over payment because consent is predicated on a clear understanding of the research, payment, and what is involved for the participant, including any risks to them as a result of participation in the research activities, and any supports they need.

5.3. Utility of Existing Guidelines and the Need for a Contextual Framework for Decision-Making

The references to specific guidelines within and across the papers included in this review show that the guidelines used in relation to the payment of 'vulnerable' groups are often incomplete and, where they are specific, sometimes conflict. There was no consistency across the guidelines, and variations did not appear to represent different cultural understandings of payment risks. While our discussion here has shown that context is essential to understanding payment, many guidelines do not specifically discuss the context of those deemed to be vulnerable, even where they are identified as groups needing additional protections in broader guidelines within the same jurisdiction (e.g., National Health and Medical Research Council 2007, 2019). Guidelines can provide broad guidance, but without consideration of the research context, or the ethical frameworks surrounding them, it is not possible to consider clearly how decisions should be made in relation to people with disability (McGregor et al. 2023). With this in mind, it is important to map out a framework which considers the research context and focuses on individual interests and needs while considering the broader communities in which the individual is situated. Figure 2, below, provides a diagrammatic portrayal of the different elements that should be considered when determining whether and how to pay participants with disability.

This diagram is preferable to a list of questions that can be worked through because it encourages a broad understanding of the research environment, rather than a tick-box exercise, which may miss the most relevant aspects of a particular research context. The diagram includes the following key elements: the research environment; research situation; participant group; risks and benefits of the research; individual context; relational context; and research practices. The research environment refers to the institutional and research-team context relevant to the project, which impacts on the extent to which the needs and interests of people with disability will be understood and respected. It considers any practical issues, such as project budgets, which may impact payment, as well as important issues about the extent to which participant experiences are likely to be interpreted and

understood by the research team. From the perspective of the second author who is a researcher with the lived experience of disability, shared experiences with study participants with disability can help to reinforce the importance of ethical payment practices within the research environment. For example, the neurodivergent author's previous experiences with ableism where they were expected to participate in studies for little or no monetary compensation motivates them to be considerate of the financial needs of study participants with disability. The research situation refers to the broader cultural context in which the research is taking place, including the social, economic, and historical context in which the research is situated. This context can impact on the rates and types of payment and other contextual factors which might constrain or enhance decision-making around the payment. Considering the participant group necessitates the researchers gaining a clear understanding of the situation of the group of people with disability that are being invited to participate in the research and any relevant contextual factors which may be relevant to the payment for participation and their decision-making around participation. This includes consideration of different approaches to payment that may reflect cultural differences and the intersectional needs of participants and participant groups. It should also consider any stereotypes surrounding people with disability, which might lead to assumptions about capacity, payment types and rates, and so forth. An understanding of the participant group is best gained by developing connections with the community that the potential participants belong to. The actual research risks and benefits are important to consider because they draw attention to the consequences to the participant of the decision to participate or not, and are essential in considering justice, reciprocity, and the consequences to the research of not including their voice.

The individual participant forms a part of the research context; however, they are usually ignored in decision-making around payment, given that payment decisions are usually made at the ethics approval step before data collection commences. However, decision-making about payment should be seen as a continuing negotiated process which extends beyond this step. The individual participant is sometimes forgotten in the procedural aspects of the consent process which can be reduced to information provision through an information sheet and consent form. Considering the individual participant's situation and their individual, sometimes intersectional, needs is integrally linked to the researcher–participant relationship. All research should include space for the participant's own views and the understanding to enter the broader research participation process, which are essential to the processes of consent. The research approach and overall methodological context of the research is important to this. Qualitative research allows and necessitates deeper relationships to be built between researchers and participants with disability, which means that the researcher is able to better connect with the individual's situation, and they can determine together through "opening questioning" whether they are freely consenting or being unduly influenced by payment (Warnock et al. 2022). From the second author's lived experience perspective, lived experience-led and co-produced research where research team members have the lived experience of disability can support open and honest exchanges with study participants with disability on a range of conversational topics, including those of consent and payment. Consideration should also be given to what supports individuals may need to be able to consent where this is recognised as needed by the person with disability. All parts of this framework are relevant to the decision-making processes concerning the payment of participants with disability in research and should be considered part of the ongoing process of the research, rather than a process that ends at the initial payment decision.

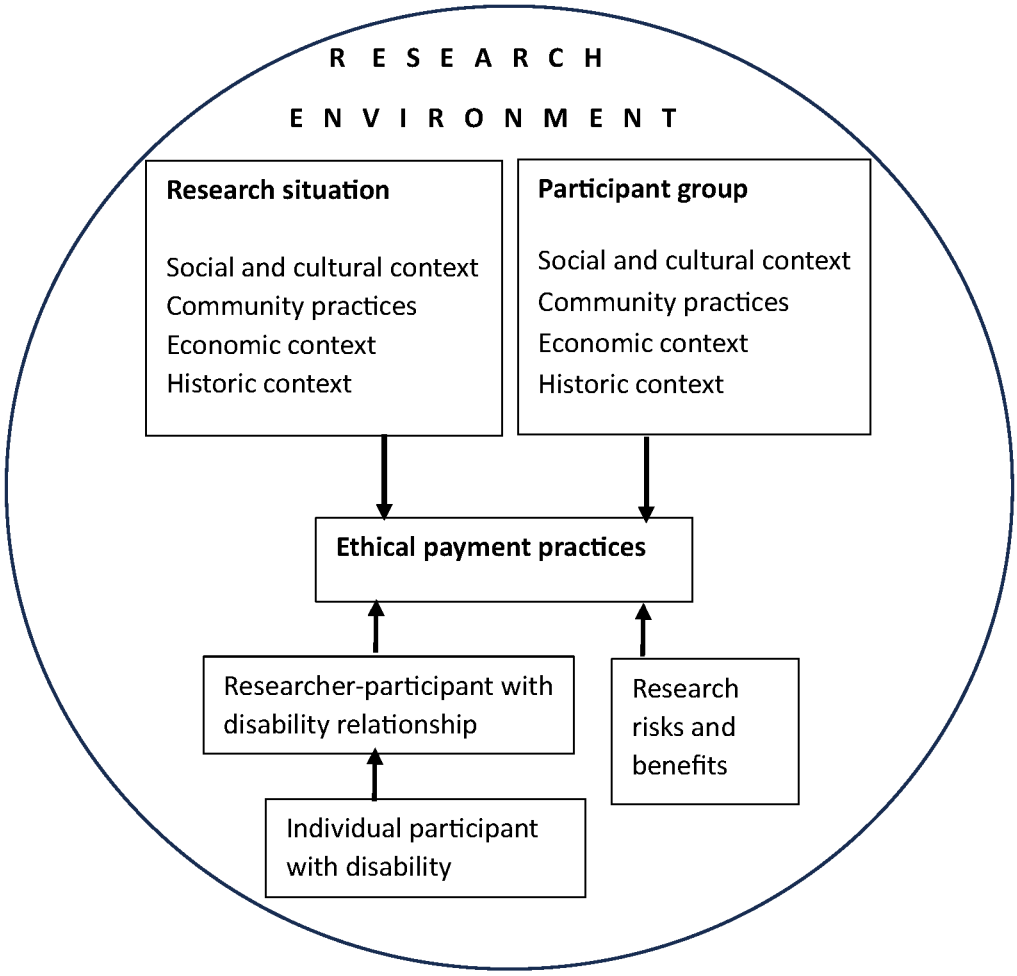

Figure 2. Decision-making framework.

5.4. Limitations

The scoping review methodology in this article followed the PRISMA-ScR guidelines (Tricco et al. 2018) but may have been enhanced by having two rather than one reviewer checking the papers against the inclusion criteria. Relying on a sole reviewer could have meant that some relevant papers were missed from the review. The review only identified 15 papers, and the studies themselves included many expert discussions that did not contain empirical research. Of those that did contain empirical research findings, one paper did not fully report its methodology (Roca and Bates 2014), and only three papers included discussion of low- and middle-income countries. Because of the small number of papers, an effective comparison between contexts and types of research was not possible. This limits the data relied on in the review and therefore the reliability of the framework derived from it. However, the discussion is an important step in considering how we can conceptualise the contextualisation of the payment of people with disability in research, and the framework provides an initial structure from which to consider the dimensions of the payment practices. We aim to apply this framework to a further study in progress which is examining the current practices of the payment of participants in research in an Australian setting.

6. Conclusions

This paper has provided an overview of the existing literature relevant to consideration of the payment of research participants who are positioned as 'vulnerable'. The main findings of the review have been synthesised and a framework co-developed with the aim

of assisting researchers in their decision-making surrounding the payment of people with disability in research. This framework should be tested through use in research to understand its useability and acceptability by those with disability and the broad community of researchers working in disability research. It is also important for the broader findings of the research to be considered part of the development of national guidelines for the payment of research participants. There is an urgent need to review the existing guidelines because of the current failure to give guidance to researchers that really address the needs of individuals considering research participation. As highlighted within the perspectives provided by the second author with the lived experience of disability, included among these possible needs is payment for research participation. The findings and framework co-developed in this paper underline the need for the development of a contextual approach to vulnerability to transplant simplistic categories of vulnerability which ascribe narrow and often stereotypical characteristics to individuals simply because they are identified with a particular group.

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